



Suffolk
Safeguarding
Partnership

Sudden or Unexpected Collapse and Death in Infancy or Childhood (SUDIC)

Protocol (0-18 years)

The protocol contains general guidance about responding to unexpected collapses and deaths in infancy or childhood and information about individual agency responsibilities. It describes some of the factors that may raise concern about a death in infancy or childhood.

Policy Version History

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A. Introduction and Background

This protocol represents the local operational agreement of agencies and must be read in conjunction with the [Royal College of Paediatrics and Child Health Sudden unexpected death in infancy and childhood](#) and [Working Together 2018](#) guidance.

This protocol should also be read in conjunction with the [Child Death Review Statutory and Operational Guidance \(England\) \(2018\)](#).

The majority of sudden unexpected deaths in infancy or childhood have natural causes and are unavoidable tragedies. The incidence of unexpected deaths in infancy or childhood is highest in infants under six months. About 600 babies die suddenly and unexpectedly each year in the UK.

The principles of this protocol should also be considered for any unexplained collapse likely to lead to the death of a child and should be applied throughout the protocol and should include children up to and including their 18th birthday.

Professionals from a number of different agencies and disciplines will become involved following an unexpected death in infancy or childhood to try to establish the cause of the death and support the family. This protocol is intended to provide guidance to the professionals confronted with these tragic events. It is acknowledged that each death has unique circumstances and each professional has their own experience and expertise to draw on in their handling of individual cases. There are, however, common aspects to the management of unexpected death in infancy or childhood and it is important to achieve good practice and a consistent approach.

All professionals need to strike a balance between managing the sensitivities of a bereaved family and identifying and preserving anything that may help to explain why the child died. It is as important to absolve a family from blame and to recognise medical conditions, especially hereditary disorders, as it is to identify unnatural deaths or homicides.

B. Key Principles of the SUDIC Protocol

When dealing with an unexpected death in infancy or childhood, all agencies need to follow five key principles:

- Sensitive, open minded, balanced approach.
- Inter-agency Response.
- Sharing of Information.
- Appropriate response to the particular circumstances.
- Preservation of Evidence.

These key principles are each of equal importance.

HM Coroner must be informed at the earliest opportunity of any unnatural or sudden death of unknown cause. HM Coroner has control of what happens to the child's body and decides which pathologist will complete the post-mortem examination.

Individual cases can always be discussed with a Coroner's Officer or, in an emergency, with HM Coroner directly. HM Coroner should normally be contacted via the Coroner's Office.

C. Application of the SUDIC Protocol

The protocol should be applied to all initially unexpected and/or unexplained deaths of Suffolk infants, children and adolescents up to their 18th birthday. This includes all sudden accidental deaths, road traffic collision deaths and where sudden, unexpected collapse is expected to lead to death.

The principles of the protocol will still apply to initially unexpected and/or unexplained deaths of Suffolk infants or children who die outside of Suffolk. If the death occurs in the UK, Suffolk professionals should liaise with out of county colleagues who will be following similar guidance. The principles also apply to Suffolk children whose deaths occur outside of the UK. In these circumstances, early liaison with HM Coroner will be essential to ensure optimum service provision to the affected parties.

Definition: SUDIC (sudden unexpected death in infancy/childhood) also known as JAR (Joint Agency Response)

A SUDIC or Joint Agency Response should be triggered if a child's death:

- is or could be due to external causes (including suicide, accidental, trauma);
- is sudden and there is no immediately apparent cause;
- occurs in custody, or where the child was detained under the Mental Health Act;
- where the initial circumstances raise any suspicions that the death may not have been natural; or
- in the case of a stillbirth where no healthcare professional was in attendance. Excludes all other stillbirths of termination carried out within the law.

All of the above circumstance and where in doubt, the first step in this protocol is to hold an initial decision-making meeting as soon as practicable but within 2 hours, with the Police SIO, EDS Operational Manager or Head of Safeguarding and Consultant Paediatrician (and CDR team in hours) by phone or Teams. This is particularly important where there is any question over whether the SUDIC protocol should be applied. (see appendix 4, examples)

A SUDIC (Joint Agency Response) should also be triggered if such children are brought to hospital near death, are successfully resuscitated, but are expected to die in the following days. In such circumstances the Joint Agency Response should be considered at the point of presentation and not at the moment of death, since this enables an accurate history of events to be taken and, if necessary, a 'scene of collapse' visit to occur.

The protocol excludes those babies who are stillborn (except where unattended by a health care professional) and planned terminations of pregnancy carried out within the law.

* Every child death is reviewed following the [Child Death Review Statutory and Operational Guidance \(England\) October 2018](#). Please refer to this as it includes all the necessary information regarding cases which fall outside of SUDIC process.

SUDIC / Joint Agency Response

**Immediately
Within 1-2
Hours**

Ambulance/police immediate response. Assess risks/concerns; resuscitate if appropriate. Police to consider appropriate scene security Consider needs of siblings and other family members.

Safety of siblings must be considered. Admit twin/multiple birth siblings for examination.

**In all cases of unexpected death, these children should be taken to ED unless clearly inappropriate. (subject to agreement of SIO)
In all cases and where in doubt a tripartite discussion between health (CDR team and/or consultant paediatrician), Social Care and Police to be held immediately**

**First 24
Hours**

CDR Team notified of child death/sudden collapse on 01473 770089

Hospital staff/ CDR team/ police agree who will inform relevant professionals and agencies (including CYPS EDS). Police inform HM Coroner Completion of Death Notification Form by CDR Nurse

On call hospital paediatrician confirms death/sudden collapse. Paediatrician, jointly with SIO takes initial history and where death has occurred, completes examination. CDR Nurse key worker identified and family given *When a Child Dies*, booklet with their key worker contact details. Family supported by CDR Nurse (ED staff out of hours handed over to CDR Team next working day). Police investigation on behalf of HM Coroner commences. Information sharing discussion between health, police, Social Care. Need for SUDIC strategy meeting and home visit agreed.

CDR nurse and/or Paediatrician provide report for coroner/pathologist

**24 -48
Hours**

Joint home/scene of collapse visit by police and CDR Nurse (or paediatrician between 4pm and 8am Monday to Friday or Weekends **only** in exceptional circumstances)

**3
Months**

SUDIC Strategy meeting convened/chaired by Senior Social Care Manager. Attended by CDR Nurse, Consultant Paediatrician, Ambulance Crew, Police and where relevant: Education/Nursery, GP, Social Worker, Coroner's Officer, Health Visitor/School Nurse (via NNSC) and any other professional who can provide information to assist the investigation. Minutes shared with CDOP co-ordinator.
CDR Nurse completes Reporting form on eCDOP

Preliminary and final post-mortem examination report provided to the coroner, and with agreement shared with the CDR Team.

Coroner arranges Post-mortem examination

Final review SUDIC meeting takes place within 3 months or once the post-mortem results have been received. Chaired by Senior Social Care Manager if safeguarding concerns or CDR Nurse if no safeguarding concerns.
CDR Nurse completes drafts analysis form on eCDOP and sends to coroner

Report of review SUDIC shared with CDOP Co-ordinator.

**Within 6
Months**

Coroners' pre-inquest and inquest

Child Death Overview Panel

E. General Advice for Professionals when Supporting the Family

This is a very difficult time for everyone. The time spent with the family may be brief, but events and words used can greatly influence how the family deals with their bereavement in the long term. It is essential to maintain a sympathetic and supportive attitude, whilst objectively and professionally seeking to identify the cause of death.

Remember that parents, family and/or carers are in the first stages of grief. They are likely to be shocked and may appear numb, withdrawn, angry or very emotional. Professionals should always consider the parents, family and/or carers views and ensure the SUDIC process is flexible and sensitive.

- The child should always be referred to and handled as if he or she were still alive and his or her name used throughout.
- Professionals need to take account of any religious and cultural beliefs that may have an impact on procedures. Such issues must be dealt with sensitively, whilst maintaining a consistent approach to the investigation.
- All professionals must record any history and background information given by parents or carers in detail. Initial accounts about circumstances, including timings, must be recorded verbatim.
- It is normal and appropriate for parents, family and/or carers to want physical contact with his or her dead child. In all but very exceptional circumstances this should be allowed with discreet observation by an appropriate professional.
- Parents, family and/or carers should always be allowed time to ask questions and be provided with information about where their child will be taken and when they are likely to be able to see him or her again.
- Parents, family and/or carers should always be made aware that HM Coroner may be involved and that a post-mortem examination will be necessary.
- Staff members from all agencies should be aware that on occasions, in suspicious circumstances, the early arrest of parents or carers may be essential in order to secure and preserve evidence and to conduct the investigation. Professionals must be prepared to provide statements of evidence promptly in these circumstances.
- A Child Death Review Nurse will be assigned to the family as the key worker and where appropriate lead health professional to support the family and coordinate health's response throughout the child death review process.

* Please refer to [Managing Child Deaths in Suffolk](#) for all deaths which occur in children who have pre-existing life limiting medical or life-threatening conditions or where the death was expected.

1.0 Child Death Review (CDR) Team

- 1.1 In 2019 a new CDR team was set up for Suffolk. The purpose of this team is to ensure a more effective process that runs from the moment of a child's death/acute life threatening event (ALTE) to the completion of the review by the Child Death Overview Panel (CDOP). To ensure the process is as standardised as possible the CDR Nurse will take the role of the lead health professional and key worker, being a point of contact for information sharing and effective communication for the family and professionals. The CDR Nurses will ensure that every family no matter how their child has died will be offered support throughout the Child Death Review Process.
- 1.2 Following the death of a child the CDR team will be notified and will attend the Emergency Department to meet the police and initiate support for the family.

For West and East Suffolk:

The CDR Team are available Monday to Friday, 08.00 – 16.00

Contact: 01473 770089

Outside of these times, all child death notifications will be picked up by the team on the next working day.

For Waveney:

The Norfolk Child Death Review Team provides cover for Waveney and is available Monday to Friday, 08.00 –18.00.

Contact: 01603 257160

2.0 Ambulance Service

- 2.1 Following the receipt of a call to the Ambulance Control Centre, the nearest available Emergency Response will be sent to the scene, supported by a second Emergency Response if possible.
- 2.2 On Emergency Response arrival, the child will be assessed (Joint Royal Colleges Ambulance Liaison Committee, 2013).
- 2.3 If required, Advanced or Intermediate Life Support will be commenced with immediate transport to the nearest Emergency Department, with a Hospital Pre-Alert call of expected time of arrival.
- 2.4 The crew attending the scene will obtain the history of events and observe the scene and position of the child on their arrival and should include these details on the Patient Report Form.
- 2.5 Following the assessment and all checks for signs of life, combined with the history of events, if the infant is obviously dead the crew on scene will recognise death, inform the parents or carers

and liaise with Police. They will provide a Recognition of Life Extinct form to the Police (Joint Royal Colleges Ambulance Liaison Committee, 2013).

- 2.6 The crew will await the arrival of the Police Designated Senior Investigating Officer (SIO) and wherever possible the Operational Ambulance Duty Officer will attend.
- 2.7 The SIO will make the decision if the scene is a crime scene. In this case, a discussion must take place between the SIO and the Senior Ambulance Officer available as it may be appropriate for the child to be left on scene. In these circumstances the SIO or his nominee will sign the Ambulance Patient Report Form. A copy will then be kept by the SIO. The Ambulance will then clear from scene.
- 2.8 For all other circumstances the Ambulance Service will co-ordinate and provide support for the family and then liaise with the SIO to decide whether the body is taken to the Emergency Department or the mortuary.
- 2.9 With the agreement of the SIO, the Ambulance Crew will transport the deceased child and immediate family to the nearest Emergency Department with a Hospital Pre-Alert call of expected time of arrival. For all child deaths, including 16-18 year olds, the Paediatrician on call should be consulted for advice and/or to complete the home visit.
- 2.10 On receiving the Hospital Pre-Alert call, the Emergency Department should prepare two rooms. On arrival, the parents, family and/or carers should be shown into one room and then the infant or child should be taken into another room for handover to the Emergency Department staff, Consultant Paediatrician and CDR Nurse.
- 2.11 The Ambulance crew should then be stood down from Operational Duty for a period of down time and welfare arranged by the Operational Duty Ambulance Officer.
- 2.12 The Ambulance crew will assist the Police in providing a witness statement as soon as practicably possible after the event and will share information with the CDR Nurse.
- 2.13 The Ambulance crew will make every effort to attend the SUDIC Strategy Meeting in order to assist the Joint Investigation Team in the enquiry. Where this is not appropriate or available the CDR Nurse will liaise with the crew and share their information at the SUDIC strategy.

3.0 General Practitioners

- 3.1 There are times when a GP is called to attend the child first. In such circumstances the GP should adhere to the same principles as the Ambulance Service (see Section 2).
- 3.2 It is essential for the GP to contact the Police or HM Coroner's Office if they are the first on the scene, after taking into account their primary responsibility of saving life or declaring death. Contact Police Headquarters on 101 or 01473 613500.
- 3.3 A GP may not issue the death certificate if the death is unexpected.

4.0 Police

A Joint Agency Response/SUDIC should be triggered if a child's death:

- is or could be due to external causes;
- is sudden and there is no immediately apparent cause;
- occurs in custody, or where the child was detained under the Mental Health Act;
- where the initial circumstances raise any suspicions that the death may not have been natural; or
- in the case of a stillbirth where no healthcare professional was in attendance.

In any of these circumstances or if in doubt, the on-call health professional (CDR Team and Consultant Paediatrician), police investigator, and duty social worker should hold a tripartite decision-making strategy discussion immediately so as to initiate the SUDIC joint agency response.

4.1 Overview

- 4.1.1 This protocol is compliant with The National College of Policing 'Guidance on Child Abuse' (refreshed version of the ACPO 2009 Guidelines on Investigating Child Abuse and Safeguarding Children') and, where appropriate, reference should also be made to the ACPO 'Murder Manual'. Also, the 2014 NPCC 'Guide to Investigating Child Deaths'.
- 4.1.2 Throughout this protocol there will be references to key tasks, which officers either attending or managing the investigation will need to take into consideration.
- 4.1.3 It is important for police officers to remember that most unexplained child deaths have natural causes. Police actions therefore need to be a careful balance between consideration for the bereaved family, and the possibility that a crime has been committed.

4.2 Who Should Attend?

- 4.2.1 Initial resource deployment will be at the discretion of the Contact and Control Room and will be influenced by the location at which the apparently dead child has been reported to be. Many of these deaths will involve police attendance at Hospital Emergency Departments, where actions will be necessarily different to those where police attend other premises. Police attendance should be kept to the minimum required. For example, several police officers arriving at a private house can be distressing, especially if they are uniformed officers in marked police vehicles.

Whenever possible, consideration should be given to the initial response being from plain clothed specialist officers, but this may not be possible if an emergency response has been requested.

- 4.2.2 In any event, an officer of not less than the rank of Detective Inspector will be the Designated Senior Investigating Officer (SIO) in the first instance. In core hours this will be a Detective Inspector from the Safeguarding Investigation Unit (SIU). There may be variations for example a road traffic collision when specialist SIO's will come from the Serious Collision Investigation Team, or homicide (which will feature the Major Investigation Team, but they would work with the SIU who will manage the SUDIC process, as opposed to the investigation).
- 4.2.3 If subsequent assessment considers the death to be suspicious then the on-call Force SIO will be contacted and take the lead role in the investigation, assisted by the SIU.

4.2.4 Where the deceased child is at an Emergency Department, consideration must be given to the deployment of resources at the address from which the child came, prior to the child's attendance at the Emergency Department. Officers maintaining the integrity of any such scene should use unmarked vehicles where possible and **NOT** use cordon tape unless at the explicit instruction of the SIO.

4.3 Initial Action at the Scene

4.3.1 The first priority (as in any such case) will be the provision of medical assistance to the child.

4.3.2 Where appropriate, the Designated SIO should contact the on-call Consultant Paediatrician at the hospital and CDR Team.

4.3.3 If an ambulance is not present one must be called immediately, and consideration given to attempting to revive the child, unless it is absolutely clear that the child has been dead for some time. (Ambulance Service Personnel will remain on scene until their release is confirmed by the Designated SIO).

4.3.4 Officers in attendance will need to show compassion and sensitivity. Careful thought needs to be given to the use of police radios and mobile telephones. Police terminology such as "scene of crime" should be avoided. Good practice is to establish and use the child's name whenever referring to the child.

4.3.5 An officer of not less than the rank of Detective Inspector will attend as the Designated SIO (subject to the exception re road traffic collision at 3.4 above). In core hours this will be from the SIU. Amongst other considerations, he/she will:

4.3.6 Consider release of Ambulance Service Personnel and vehicle as soon as possible; ensure arrangements are made to secure all relevant documentation.

4.3.7 Arrange liaison with the County Safeguarding Manager to prompt a SUDIC Strategy Meeting. If the death occurs out of hours, notify the Head of Safeguarding or their nominated deputy, normally via the CYP Emergency Duty Service (for contact details, see Section 6).

4.3.8 Ensure the Child Death Review Nurse Team has been informed and given contact details to support the family.

4.3.9 HM Coroner must be notified as soon as possible. Depending on when the investigation commences this may be through Coroner's Officers. As well as the usual functions they perform, their experience in dealing with sudden deaths and bereaved family will be invaluable in explaining to the parents, family and/or carers what will happen to their child's body and why. It may be of assistance for Coroner's Officer to attend the scene and then liaise directly with HM Coroner as required or at the direction of the SIO. The
SIO and Coroner's Officer should continue to liaise closely throughout the investigation.

4.3.10 An explanation should be given, where appropriate, to the parents, family and/or carers that police attendance at such deaths is routine in order to try and determine how the child died.

4.3.11 An early record of events from the parents, family and/or carers is essential, including details of the child's recent health. All comments should be recorded. Any conflicting accounts should raise suspicion but it must not be forgotten that any bereaved person is likely to be in a state of shock and possibly confused. Repeated questioning of the parents, family and/or carers by different police officers should be avoided at this stage if at all possible.

4.4 Initial Action at the Hospital

- 4.4.1 The SIO or delegated officer will attend the Emergency Department (ED) as soon as practicable in order to consult with the Senior Consultant Paediatrician in order to jointly review the presenting information and to consider the appropriate course of action.
- 4.4.2 Child Death Review Team are notified and asked to attend the ED if between Monday to Friday 8am to 4pm or if out of hours, handed over by the receiving Consultant Paediatrician to the CDR team next working day Paediatrician in charge has discussion with police to determine appropriate setting for the body to be taken to. This will normally be the Emergency Department.
- 4.4.3 Issues such as handling of the deceased child will require particular care and sensitivity. This should be minimal by medical staff only until a full assessment of the situation can be made by the SIO in conjunction with the Senior Consultant Paediatrician.
- 4.4.4 In any event, the deceased child must not be removed from the ED until after the SIO/ Senior Consultant Paediatrician have had their joint discussion.
- 4.4.5 During this joint discussion consideration will be given to forensic and pathology issues which should include retention of the deceased child's clothing, nappy and contents.
- 4.4.6 If the child has been certified as deceased then details of the person declaring death must be obtained as well as the relevant time. Similarly, details of any Ambulance Personnel or method of transport of the deceased child to the ED, together with what sort of medical intervention or assistance attempted, must be established for the information of the SIO.
- 4.4.7 Attendance at the ED should be kept to a minimum and consideration must be given to preserving any other place as a potential scene of where death occurred.

4.5 The Scene

- 4.5.1 The preservation of the scene and the level of investigation will be relevant and appropriate to the presenting factors.
- 4.5.2 Officers initially attending the scene should ensure it is preserved until such time as the SIO gives any further instruction. Any relevant items should be drawn to the attention of the SIO, who will assess the circumstances and information available. Additional resources such as photographers will be considered at this stage and the SIO will decide what items, if any, will be retained or removed from the scene.
- 4.5.3 If it is necessary to remove items, this will be done with due consideration for the parents/carers, who should be asked if they want the items returned at an appropriate time.
- 4.5.4 If parents, family and/or carers ask to hold the deceased child this can be permitted but should be done with the knowledge of the SIO and in the presence of a Police Officer or other professional.

4.6 Other Issues

- 4.6.1 In all cases HM Coroner will be kept informed of the progress of the investigation and issues for consideration will include:
- Completion of Sudden Death Pro-forma Documentation and Report for HM Coroner.
 - Identification and continuity of identification of the deceased child.

- Attendance at post-mortem examination.
- Tissue and organ retention.

4.7 Away from the Scene

4.7.1 In all but exceptional circumstances (e.g. at an obvious murder scene when police response will be in accordance with the ACPO Murder Manual) the body of the deceased child will be conveyed by Ambulance to the relevant ED.

4.7.2 If the parents, family and/or carers wish to accompany the child's body from the home to the ED, then this should be facilitated. They must be accompanied by a Police / Coroner's Officer.

4.8 Subsequent Actions

4.8.1 The SIO or his/her nominee, (in certain circumstances a Family Liaison Officer may be appointed), will continue to maintain contact with the parents, family and/or carers and keep them informed of any developments.

4.9 Joint Home Visit

4.9.1 When a child dies unexpectedly the SIO and the Child Death Review Nurse should, where appropriate, plan a joint visit to the place where the child died.

4.10 SUDIC Strategy Meeting - Ideally within 24 Hours

4.10.1 The SIO will attend in accordance with the joint agency protocol. It should be exceptional only that the SIO who initially deals with the SUDIC is not present at this critical meeting and cover arrangements should be addressed to facilitate this. Where the Serious Collision Investigation or Joint Major Investigation Teams are investigating the death, the SIO or Deputy SIO's attendance should also be arranged.

4.11 Review SUDIC Strategy Meeting

4.11.1 Within 12 weeks after death a detailed post-mortem examination report should be available and the investigation completed. A multi-agency professionals meeting chaired by a County Safeguarding Manager should then take place. This should include those involved in the care of the child and family to include the Health Visitor, School Nurse, Police, GP, Coroner's Officer, receiving Consultant Paediatrician, Education staff either school or education safeguarding team County Safeguarding Manager and where appropriate, the Social Worker. If there are no safeguarding concerns then this meeting may be led by the CDR team. This meeting will represent the final child death review meeting.

4.12 Retained Items

4.12.1 At the earliest opportunity after enquiries are completed, (after consultation with Coroner's Officer), any items the parents, family and/or carers wish to have returned, should be returned to them.

4.12.2 All police documentation will be removed and the property will be returned if appropriate in new/clean wrapping/bags. If soiled articles were taken, parents, family and/or carers should be asked about their return, and if they would like them cleaned prior to return.

- 4.12.3 An appointment should be made with the parents, family and/or carers to return any property, remembering that this could be a significant event for them in terms of their bereavement.

5.0 Hospital Staff

5.1 Overview

Hold an initial decision-making meeting as soon as practicable but within 2 hours, with the Police SIO, EDS Operational Manager or Head of Safeguarding and Consultant Paediatrician (and CDR team in hours) by phone or Teams. This is particularly important where there is any question over whether the SUDIC protocol should be applied. Remember there will be a review of every child death by the CDR process, and that an internal hospital review process may also occur independent of the SUDIC process.

- 5.1.1 The child will **not** be taken straight to the mortuary unless directed to do so by the Designated SIO. Ensure that the child is taken to the appropriate area of the ED even if they appear to have been dead for some time.
- 5.1.2 Find out the identity of the people accompanying the child and their relationship to the child. Use the child's first name.
- 5.1.3 Notify the Child Death Review Nurse Team and a CDR Nurse will, attend the ED and be allocated to the family
- 5.1.4 Consider admission of siblings. Always consider the admission of a twin or multiple births.
- 5.1.5 When out of hours for the CDR team the hospital should allocate a Nurse to look after the parents, family and/or carers to keep them informed about what is happening. The Nurse should record any medical or other information they obtain. This Nurse will then handover ongoing care of the family to the CDR Nurse next working day
- 5.1.6 A discreet presence of a member of staff should be at all times even when a family and/or carers wishes to be alone with their child after their death. A member of staff should keep them informed about what is happening.
- 5.1.7 Ensure that a copy of the Information for families following a bereavement has been given to the parents, family and/or carers.
- 5.1.8 Complete the Hospital Infant and Child Sudden Death Checklist (Appendix II).
- 5.1.9 Ensure that the County Safeguarding Manager has been notified to prompt a SUDIC Strategy Meeting. If the death occurs out of hours, notify the Head of Safeguarding or their nominated deputy, usually via the CYPS Emergency Duty Service (for contact details, see Section 5).

5.2 History and Examination (Kennedy Report, 2004 pg. 30)

- 5.2.1 An initial history should be taken while resuscitation is underway. A history and examination, with due consideration to the acute bereavement felt by the family members, are extremely important in the process of trying to identify the cause of death. Appendix I provides a proforma to be completed by the Consultant Paediatrician (as used by the Pathologist) at the home visit.

5.2.2 A full examination should be undertaken by a Consultant Paediatrician and a careful record of any findings made on a body chart. Photographs should be taken of any injuries, subject to discussion with the Designated SIO.

5.3 Emergency Department

5.3.1 During the process of resuscitation various investigations will be initiated, samples will be taken as appropriate (see Appendix III) and child weighed and weight recorded in the medical record (see Appendix II).

5.4 HM Coroner

5.4.1 Once the attending Consultant Paediatrician has confirmed death, HM Coroner assumes immediate responsibility for the body.

5.4.2 HM Coroner has given consent in Suffolk to an agreed set of samples to be taken in SUDIC circumstances, without the need for hospital staff to seek prior approval from the parent/s or HM Coroner's Office in each case (see Appendix III).

5.4.3 The Consultant Paediatrician should send the Pathologist details of the child's recent and past medical history, resuscitation attempts at home and hospital including needle sites, any physical findings and any investigations, via HM Coroner's Office.

5.5 Recommended Information to be collected by the Consultant Paediatrician and/or Child Death Review Nurse at the First Interview and the Home Visit (Appendix I)

5.5.1 When the child is pronounced dead, the Consultant Paediatrician should break the news to the parents, family and/or carers and review all the information. The Consultant Paediatrician should explain that investigations will be done into possible medical causes of the death; that the Police and HM Coroner also have to investigate the death; and that HM Coroner will order a post-mortem examination by a Pathologist with special expertise.

5.5.2 Parents/carers should be able to hold and spend time with their child after agreement with the Consultant Paediatrician and Designated SIO. If resuscitation is attempted, intravenous and intra-arterial lines and endotracheal tube should be removed (checking that the tube had been correctly placed). **Professional presence must be discreet during parents, family and/or carers time with their child.**

5.5.3 Inform parents, family and/or carers that a Child Death Review Nurse and Police Officer will visit them at home in the next 1-2 days to talk more about what has happened. Parents, family and/or carers should be given contact details for the Child Death Review Nurse Team and Police Officer.

5.5.4 The Emergency Department will discuss how the parents, family and/or carers are getting home and will inform all relevant professionals and agencies about the death (i.e. GP, Health Visitor, Records Departments, etc.) using the Death Notification Form and discuss contacting friends, family, employers, etc.

5.6 Post-Mortem Examination Results

5.6.1 HM Coroner's Office will issue or disclose post-mortem examination results to relevant parties.

5.6.2 The Consultant Paediatrician will offer to meet the parents, family and/or carers again to discuss the post-mortem examination findings and any other questions.

6.0 CYPS and Emergency Duty Service (EDS)

6.1 Out of hours

- 6.1.1 In the case of a SUDIC out of hours, the on call EDS Social Worker will be notified by Police or Hospital Staff.
- 6.1.2 The EDS Social Worker will inform the Out of Hours Duty Manager and they will be responsible for liaising with the Head of Safeguarding or their nominated deputy.
- 6.1.3 An initial strategy discussion will be held as soon as practicable with the Police SIO, EDS Operational Manager or Head of Safeguarding and Consultant Paediatrician. The next working day, the County Safeguarding Manager will co-ordinate any subsequent SUDIC strategy Meeting during office hours.
- 6.1.4 The contact telephone number for the EDS is 0808 800 4005.

6.2 SUDIC Strategy Meeting

- 6.2.1 When the death is unexplained a multi-agency Strategy Meeting will be chaired by a County Safeguarding Manager within 24 hours of the child's death to share information relevant to the investigation of the death, and support of the parents, family and/or carers.

6.3 The purpose of the SUDIC Strategy Meeting

- 6.3.1 For each agency to share information from current or previous case notes or other records which may shed light on the circumstances leading up to the child's death. This includes previous and current medical and family history to help exclude a possible underlying medical condition, child protection issues, previous unexplained or unusual deaths in the family, parental substance misuse, violence etc.
- 6.3.2 To ensure that a coordinated bereavement care plan is in place to support the parents, family and/or carers. This should include information about the Child Death Review process.
- 6.3.3 To ensure a co-ordinated plan for peers/school support as appropriate. The relevant school should be involved as soon as possible to enable them to put strategies in place for supporting other students, parents and staff that may be affected. Communication with schools is possible and should be encouraged during school holidays.
- 6.3.4 To enable consideration of any child protection risks to siblings or other children in the household and referral under child protection procedures.
- 6.3.5 To nominate a named professional to share Post-Mortem results with the parents, family and/or carers.
- 6.3.6 To set the date for the Review SUDIC Strategy Meeting within 12 weeks of the death.
- 6.3.7 To consider, where appropriate, referral to the LSCB Serious Case Review Panel.

- 6.3.8 To ensure, where appropriate, notification to OFSTED takes place in the case of a death of a looked after child or child subject to a Child Protection Plan.
- 6.3.9 To liaise, where appropriate, with the Coroner's Office to ensure that a CYPS representative is able to attend the Inquest in the case of a death of a child who has received a CYPS service around the time of their death.

6.4 Contributors to the SUDIC Strategy Meeting may include:

- 6.4.1 Health – Health information gathering will be coordinated by the Child Death review Team. Information from the Doctor who declared the death, family Health Visitor, School Nurse, Named Nurses, GP, receiving Consultant Paediatrician, the Emergency Department and Ambulance Service.
- 6.4.2 Child Death Review Team who will facilitate the setting up of this meeting and establish correct Health representatives are present.
- 6.4.3 Children's Social Care
- 6.4.4 Police Child Abuse Investigation Unit
- 6.4.5 Representative of HM Coroner's Office
- 6.4.6 Designated Doctor/Nurse for Safeguarding and Child Deaths
- 6.4.7 Education staff if the child and/or siblings attended school or other education provision
- 6.4.8 In the event of a death on public grounds or property, the Borough Council Safeguarding Lead.

7.0 Review SUDIC Strategy Meeting

7.1 Overview

- 7.1.1 Within 12 weeks after death a detailed post-mortem examination report should be available and the investigation completed. A multi-agency professionals meeting chaired by a County Safeguarding Manager should then take place. This should include those involved in the care of the child and family to include the Health Visitor, School Nurse, Police, GP, Coroner's Officer, receiving Consultant Paediatrician, Education staff either school or education safeguarding team County Safeguarding Manager and where appropriate, the Social Worker. If there are no safeguarding concerns then this meeting may be led by the CDR team. This meeting will represent the final child death review meeting.

7.2 The purpose of the Review SUDIC Strategy Meeting

- 7.2.1 To share and review the outcome of the investigation.
- 7.2.2 To close the investigation if possible.
- 7.2.3 To address outstanding questions about cause, implications for family and ongoing support.

7.2.4 At this meeting all of the relevant information concerning the death, the child's history, family history and subsequent investigation should be reviewed. A report of the Review SUDIC Strategy Meeting should be forwarded to the Coroner and the LSCB Designated Person (Child Death Overview Panel Co-ordinator).

8.0 Post-Mortem, Pathologist and HM Coroner

- 8.1 If there are no suspicious circumstances, after an evaluation of initial information (from the Ambulance Service, Hospital and previous records, Primary Care, Police and Children's Social Care records), the post-mortem examination should be conducted by a Pathologist with special expertise in Paediatric Pathology. The post-mortem examination should be completed as soon as practicable after the infant's death. If during the post-mortem examination the Pathologist becomes at all concerned that there may be suspicious circumstances, they must halt the examination and inform the Police.
- 8.2 If HM Coroner has any concerns, having been made aware of all the facts, that the death may be of suspicious nature, then a Home Office Pathologist will be used in conjunction with a Paediatric Pathologist. Where a Pathologist is qualified both as a forensic and Paediatric Pathologist they may complete the post-mortem on their own.
- 8.3 Both HM Coroner and the Pathologist must be provided with a full history at the earliest possible stage. This will include a full medical history from the Consultant Paediatrician, any relevant background information concerning the child and the family and any concerns raised by any agency. The SIO is responsible for ensuring that this is done. A pro-forma is available for the Consultant Paediatrician. Consideration should be given to provision of medical notes to the Pathologist via the Coroner's Officer.
- 8.4 Coroner's Officer should inform all relevant professionals of the time and place of the post-mortem examination, including the SIO and Consultant Paediatrician. The family should also be informed.
- 8.5 The SIO will attend the post-mortem examination only if there are suspicious circumstances. If this is not possible, then he/she must send a representative who is aware of all of the facts of the case. A full Crime Scene Investigation (CSI) team, including a photographer, must attend all post-mortems conducted by a Home Office Pathologist.
- 8.6 A number of investigations will be arranged by the Pathologist at the post-mortem examination. If the Consultant Paediatrician has arranged any medical investigations before death, the Pathologist and HM Coroner must be informed and the results forwarded.
- 8.7 All professionals must endeavour to conclude their investigations expeditiously. This should include the post-mortem examination results such as histology. The funeral of the dead child must not be delayed unnecessarily.
- 8.8 The interim or final findings of the post-mortem should be provided immediately after the post-mortem examination is completed. The interim result may well be "awaiting histology/virology/toxicology" etc.
- 8.9 The final result must be notified in writing to HM Coroner as soon as it is known. The final report should then be sent to HM Coroner within 7 to 14 days of the final result being known.

- 8.10 When a Home Office Pathologist has been used, the Pathologist should provide an interim report within fourteen working days of the post-mortem examination, either verbally or in proforma. A full written report should be provided as soon as possible to the SIO normally via HM Coroner.

F. References and Resources

References

[Sudden Unexpected Death in Infancy and Childhood \(2016\): Multi-agency guidelines for care and investigation](#)

[Child Death Review Statutory and Operational Guidance \(England\) October 2018](#)

[Working Together to Safeguard Children \(2018\) 'A guide to inter-agency working to safeguard and promote the welfare of children'](#).

[Joint Royal Colleges Ambulance Liaison Committee, \(2016\): UK Ambulance Services Clinical Practice Guidelines 2016.](#)

[Managing Child Deaths in Suffolk](#)

Resources – Information for families following a child death

[When a child dies](#)

[Lullaby Trust \(formerly FSID\) Booklet 'When a baby or young child dies suddenly and unexpectedly'](#)

[Guide to Coroner Services](#)

[Victims Voice Booklet on Sudden Death and the Coroner](#)

G. Appendices

Appendix 1: SUDIC information to be collected by the Paediatrician at the first Interview and Child Death Review Nurse at the Home Visit

Appendix 2: Hospital Infant, Child and Adolescent Sudden Death Checklist

Appendix 3: Samples to be taken immediately after Sudden Unexpected Deaths in Infancy or Childhood

Appendix 4: Examples of cases that fall under the SUDIC protocol

SUDIC Appendix 1: SUDIC Information to be collected by the Paediatrician at the first interview and the Child Death Review Nurse at the home visit

Introduction

The importance of the history being taken by an experienced Paediatrician or Child Death Review Nurse, with knowledge and understanding of the care of children and sensitivity to the needs of the family, cannot be over-emphasised. This list is meant as a guide. It cannot be comprehensive, as additional specific questions may arise as a consequence of information given by the parents.

Encouraging the parents to talk spontaneously, with prompts about specific information, is likely to be better than trying to collect a structured history in the more usual way. In recording parents' accounts of events, it is important to use their own words as far as possible. Ideally, information should be recorded *verbatim*.

Much of the information is very sensitive. Parents may feel very vulnerable when asked about their sleeping arrangements, alcohol intake or drug use, so great skill is needed in asking the questions in a non-threatening way, with no implication of value judgment or criticism. Parents may ask directly if their alcohol intake has contributed to the child's death; it is very important that the interviewer does not jump to conclusions about such questions, whilst not being dishonest when asked direct questions.

The Child

- First name and family name (plus any other names by which the child may be known).
- If possible, obtain the NHS number as this may facilitate access to other records.
- Date of birth and place of birth.

The Mother

- Full name (plus any other names by which the mother may be known).
- Full address, including post code.
- NHS number if possible.
- Date of birth.
- Phone number (home number and mobile number) and phone number of any available close relative or friend (to facilitate making contact again).
- Address to which mother will be returning when she leaves the hospital, plus phone number there and the name of the person with whom mother will be staying.

The Mother's Partner and/or Father of the Child

- Full name (including any other names by which he may be known).
- Full address, including postcode.
- Date of birth.
- Phone number (home number and mobile number) and phone number of any available close relative or friend (to facilitate making contact again).

- Address to which father/partner will be returning when he leaves the hospital, plus phone number there and the name of the person with whom he will be staying.

Other members of the household (present and in the recent past)

- Names.
- Dates of birth.
- Relationship to the child who has died.

Family medical history

- A detailed account of past medical and social history of all members of immediate family and household.
- Particular note and detailed information (name, date of birth, place of birth) of any previous children.
- Also detailed information on any deaths in infancy or childhood of any offspring, siblings or other close relatives of any member of the current household (to include as much information as possible concerning date of birth, age at death, place of death, cause of death and any other known information).

Social and family history

- A detailed account of the social structure of the family and of the household, including detailed information on alcohol, tobacco and other drug use, together with information on any prescription or non-prescription medications that may have been present or in use in the household.
- Information on recent changes in composition of the household (e.g. who has come and who has gone, and for what reasons).

Detailed medical history of the Mother

- Details of past medical and social history of the mother, including any significant past illnesses or injuries.
- Detailed past obstetric history, including detailed information on the pregnancy leading to the birth of the child who has died.

Detailed medical and developmental history of the Child who has died

To include:

- Gestation.
- Birth weight.
- Perinatal or neonatal problems.
- Type of feeding (and date and reason for changing type of feeding).
- Growth, development and past assessments (e.g. Health Visitor or GP routine, well child checks).
- Immunisations.
- Any known contact with infection.
- Medication (either prescribed or over the counter).
- If possible, obtain the parent-held child health record to copy (return this to the parents after copying it); plot the weight record onto a centile chart.

A detailed narrative account of the child's feeding, sleeping, activity and health over the two-week period prior to the death This should include information on:

- Changes in feeding or sleeping patterns.
- Changes in place of sleep.
- Any social, family or health related changes in routine practices over the past two weeks.
- Any illness, accident or other major event affecting other family members in the past two weeks.

A detailed (hour-by-hour) narrative account of events within the 48 hours prior to the child being found dead A detailed description of:

- Precisely where the child was placed for sleep.
- Duration of sleeping period.
- Position at the end of the sleeping periods.
- Any changes in routine care or routine activity levels.
- Any disruptions to normal patterns.
- Information on the activity and location of all significant members of the household.
- Information on alcohol intake and recreational drug use by members of the household during this period.

The final sleep

A very careful description of when and where the child was placed to sleep, including:

- The nature of the surface.
- Clothing.
- Bedding.
- Arrangement of bedding.
- Precise sleeping position.
- Who was sharing the surface on which child was sleeping (e.g. bed or sofa).
- How often the child was checked.
- When he or she was seen or heard.
- The times at which the child awoke for feeds.
- Whether feeds were given.
- Whether they were taken well.
- Who else was in the room at each stage.
- What were the activities of others in the room.
- Were they awake.
- Where, when and by whom was the child found.
- What was the appearance of the child when found.
- What was the position of the child when found.
- Where was the bedding.
- Were there any covers over the child.
- Had the covers and the position of the covers moved.
- Were there other objects in the cot or bed adjacent or close to the child (e.g. teddies, dolls, pillows).

- Was the heating on.
- What type of heating was there.
- Were the windows and/or doors open.

Action after the Child was found

A detailed narrative account of events that followed the discovery of the child collapsed or apparently dead, to include details of:

- When, how and by whom the emergency services were called.
- Who was with the child at each stage.
- Was resuscitation attempted and if so by whom.
- Were any responses obtained from the child.
- How long did it take for the emergency services to arrive.

Further specific questions

In addition to the information outlined above, information should be collected on the parents' perception of:

- Whether the child was feeding as well as, or less well than, usual in the past 24–48 hours.
- Any vomiting.
- Any respiratory difficulty, noisy breathing, in-drawing of the ribs, wheezing or stridor.
- Excessive sweating.
- Unusual activity.
- Unusual behaviour.
- Level of alertness.
- Difficulty sleeping and/or difficulty waking the child.
- Passage of stool and urine (how often and how much).
- Were any healthcare professionals consulted within the past two weeks, the past 48 hours or the past 24 hours.
- If so, who was contacted, what was the problem described to the healthcare professionals and what advice was given.
- Was the child seen and assessed by any healthcare professional during the past two weeks.

Whilst most of the medical and social history will be obtained during the initial discussion with the parents in the Emergency Department, a very careful and detailed account of the final 24–48 hours will almost always be considerably supplemented by information collected at the time of the initial home visit and close examination of the circumstances of death.

The home interview and visit to the place where the child died can be very difficult but may also be of great value in understanding the sequence of events leading to the death. Parents commonly find this home interview, whilst stressful and sometimes painful, very helpful – the fact that the Child Death Review Nurse is willing to spend this time with them, helping to understand what has happened to their child may in itself be very important to the family and

many questions commonly arise out of this visit (in particularly in relation to the factors that may have contributed to the death).

Time will also be needed for the Child Death Review Nurse to help the parents deal with the very powerful emotions that are commonly brought out by this discussion. If conducted sensitively and with awareness of the parents' needs, this interview can have a therapeutic 'debriefing' value for the family – commonly allowing them to talk about some of their feelings for the first time. Parents have commonly reported that this home visit has been an extremely important and very positive aspect of their care.

SUDIC Appendix 2: Hospital Infant, Child and Adolescent Sudden Death Checklist

NB – tick boxes when actions completed

Parents/Carers			
Present (give details):			
Not Present	<input type="checkbox"/>	Did parents/carers witness resuscitation?	<input type="checkbox"/>
Informed by phone/other	<input type="checkbox"/>	Did siblings witness resuscitation?	<input type="checkbox"/>
Property and/or valuables			
Check with Police whether the clothes or property are required for post-mortem investigation	<input type="checkbox"/>	Given to Patient Affairs (WSH)	<input type="checkbox"/>
Fold list and seal property as per Police requirements	<input type="checkbox"/>	In the absence of the parents, belongings are given to the Police (IHT)	<input type="checkbox"/>
Given to relatives	<input type="checkbox"/>		
Memories Box/Folder			
Disposable camera and/or photographs	<input type="checkbox"/>	Lock of hair tied with a ribbon	<input type="checkbox"/>
Footprints/handprints	<input type="checkbox"/>		
ID Bands			
Wrist x 1	<input type="checkbox"/>	Ankle x 1	<input type="checkbox"/>
(if no name available, please write unknown female/male child and hospital number)	<input type="checkbox"/>		
Card label (IH only)			
Tape to chest (not on gown)	<input type="checkbox"/>	Presence of rings/dentures/pacemaker noted in RED on card	<input type="checkbox"/>
Addressograph (WSH only)			
Apply to gown	<input type="checkbox"/>	Presence of rings/dentures/pacemaker listed in property	<input type="checkbox"/>

Notification of Death labels x 3			
1 x inside A&E Department notes	<input type="checkbox"/>	1 x front of hospital notes	<input type="checkbox"/>
1 x to registration via internal post	<input type="checkbox"/>		
Hospital Notes			
Write "RIP (department)" in black ink on the front	<input type="checkbox"/>		
GP			
Inform GP within surgery hours or if out of hours and urgent, inform duty service/otherwise email details to GP surgery's safeguarding lead	<input type="checkbox"/>		
Other Health Staff – Leave details on answer phone for:			
On site Manager/Senior Manager on call	<input type="checkbox"/>	Child Death Review Team email: sneecb-ws.suffolcdr@nhs.net	<input type="checkbox"/>
Email Designated Safeguarding Team WSCCG.suffolksafeguardingchildren@nhs.net	<input type="checkbox"/>	<1 month old informed Named Midwife	<input type="checkbox"/>
Specimens			
Specimens will be taken with the knowledge of the parent/s, by HM Coroner's consent	<input type="checkbox"/>		
Written Information			
Discussed with relatives	<input type="checkbox"/>	Name and contact details of Child Death Review Team, Paediatrician and Senior Investigating Officer	<input type="checkbox"/>
When a child dies https://www.england.nhs.uk/wp-content/uploads/2018/07/parent-leaflet-childdeath-review-v2.pdf	<input type="checkbox"/>		
Bereavement Follow Up			
To be carried out by Child Death Review Team	<input type="checkbox"/>		
Religious Needs			

Would the family like the chaplain or other religious leader to be contacted? be	Yes <input type="checkbox"/> No <input type="checkbox"/>	Would the family like the child to be baptised or blessed?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Other things to note:			
Faith book available in child bereavement box for reference	<input type="checkbox"/>	Consider Language Line or Interpreter (can be arranged via Police)	<input type="checkbox"/>
Viewing of body by the siblings for the parents and/or carer to decide	<input type="checkbox"/>	Transport Home arranged	Yes <input type="checkbox"/> N/A <input type="checkbox"/>

Nurse dealing with relatives

Signature: _____

Print Name: _____

Designation: _____

Names of staff involved:

Print name/designation: _____

Print name/designation: _____

Print name/designation: _____

Print name/designation: _____

Print name/designation: _____ Immediate

Staff Debriefing Performed? Yes , No, but date set Date: _____

Named Nurse dealing with relatives (including signature, print name and designation)

Names of Staff involved, including Ambulance Crew (print name and designation)

SUDIC Appendix 3: Samples to be taken immediately after Sudden Unexpected Deaths in Infancy or Childhood (Royal College of Pathologists and Royal College of Paediatrics and Child Health Report ‘Sudden Unexpected Death in Infancy’, 2004).

Name of Child:

Dob:

Dod:

Name of Doctor:

Date samples taken:

Tick the samples have been taken and record any needle sites on this form or a body map to aid pathologist.

	Routine Minimum Samples	Send to	Handling	Test
	Blood serum: 1– 2 ml	Clinical Chemistry	Spin, store serum at 20° C	Toxicology
	Blood cultures (aerobic and anaerobic): 1 ml	Microbiology	If insufficient blood, aerobic only	Culture & Sensitivity
	Blood from Guthrie card	Clinical Chemistry	Normal (fill in card; do not put into plastic bag)	Inherited Metabolic Diseases
	Blood (Lithium Heparin): 1-2 ml	Cytogenetics	Normal - keep unseparated	Chromosomes (if Dysmorphic)
	Cerebrospinal fluid (CSF): a few drops	Microbiology	Normal	Microscopy, Culture & Sensitivity
	Nasopharyngeal Aspirate	Virology	Normal	Viral cultures, immunofluorescence, and DNA amplification techniques*
	Nasopharyngeal Aspirate	Microbiology	Normal	Culture & Sensitivity
	Swabs from any identifiable lesions	Microbiology	Normal	Culture & Sensitivity
	Urine if available	Clinical Chemistry	Spin, store supernatant -20° C	Toxicology & Inherited Metabolic Diseases
Additional Samples				
	Skin biopsy for fibroblast culture if post-mortem to be delayed by more than 12 hours. NB. This could be taken in the local mortuary by a Pathologist, but the Paediatrician will have to request this.	Local arrangements agreed between IH, WSH, Addenbrooke’s Hospital & NNUH. Record where sample sent and copy this record for local database. HM Coroner’s investigation powers allow these samples to be taken in Suffolk without requiring explicit additional permission from parents, but they must be informed, and a record must be kept.		
	Muscle biopsy if history suggestive of mitochondrial disorder.	As Above		

***Samples must be sent to an appropriate virological laboratory**

Skin Fibroblast Sampling

Skin biopsy for fibroblast culture is recommended within the Kennedy Sampling Guidelines in cases of sudden unexpected child death where an underlying chromosomal anomaly, a genetic cause or metabolic disorder may be a possibility.

Fibroblasts from skin biopsy are used to extract DNA which can be stored indefinitely. This allows future further DNA extraction and metabolic testing. The RCPCH recommend it should be considered at the time of the initial blood, csf, urine and stool samples.

The best time to take the sample is up to approximately 12 hrs of death and to process the sample and send it to the Genetics lab as soon as possible.

If the sample is taken out of hours or at the weekend it should be kept in the fridge, and sent the next working day.

The decision to take a skin biopsy must be by the Consultant Paediatrician

Examples include:

- Sudden death in babies and children under 2 years
- Suspicion of / or family history metabolic disorders in any SUDIC
- Children with complex medical/developmental needs without clear unifying diagnosis
- Consultant Paediatrician's decision – have a low threshold to take a sample if any doubt it may be helpful in the future

Consent

Skin biopsies obtained in cases of unexpected neonatal or child death should be conducted in liaison with the Coroner.

If the death is suspicious, discussion with police and coroner must take place before any investigations are carried out, including the skin biopsy. The Coroner can be contacted out of hours, if required, via the Police.

Document the discussion with the family, including both the process itself and the need for DNA and skin fibroblast storage to enable future genetic or metabolic investigation should this be needed.

Use the Rare and inherited Disease referral form.

<https://www.eastgenomics.nhs.uk/for-healthcare-professionals/genomic-tests/referral-forms-index/rare-disease-tests-non-wgs/>

NB If the samples is to be detained long term separate consent will be required in the future.

Taking the skin biopsy for fibroblast culture

Use the prepared skin biopsy kit OR a scalpel - see below. The Tissue transplant medium is in a sample pot in the fridge on Bergholt ward – check the expiry date. If it is out of date use 0.9% saline and a universal container.

Clean the front of the thigh with an alcohol wipe, or chlorohexadine solution. Rinse with sterile water and allow to dry.

1. Use the punch biopsy device. The punch biopsy instrument is held vertically over the skin and rotated downward using a twirling motion created by the first two fingers on the dominant hand. Once the instrument has penetrated the dermis into the subcutaneous fat, or once the instrument reaches the hub, it is removed.
2. Press out/ Guide the punch biopsy into the sample pot (either TTM or saline).
3. **OR:** Use the scalpel and take a skin biopsy. The skin surrounding the biopsy site is stretched with the thumb and index finger of the non-dominant hand. The skin is stretched perpendicular to the lines of least skin tension. Cut out an elliptical-shaped sample (approximately 5 mm X 2 mm) with a scalpel in the same direction as the lines of least skin tension.
4. Transfer the ellipse skin biopsy into the sample pot (either TTM or saline).
5. Use a suture or steristrips if there is some bleeding (likely to be absent or minimal) and cover with a dry dressing.
6. Label the pot and complete the Genetics form with the relevant details, indicating SUDIC/ possible underlying chromosomal or metabolic condition and as much details as you can.
7. Send to the pathology lab to store in the fridge until the sample can be sent to the Addenbookes' genetics lab in office hours. Ring lab staff at Ipswich to ensure they will do this.
Remind them - Do not freeze.
8. Remind Lab staff that **the sample should be sent to Addenbrooke's Genetics Lab the next work day.**
Please call the Cytogenomics Lab 01223 348 706 to let them know to expect a sample. Check with our pathology lab that they have sent it off.

Appendix 4

Examples of cases that fall under the SUDIC protocol

Death or collapse leading to death;

- Is or could be due to external causes
 - Suicide or fatal self-harm
 - Road traffic accident
 - Choking
 - Death due to trauma from accident or inflicted trauma such as a stabbing.
- Is sudden and there is no immediately apparent cause
 - Child is brought to hospital with no underlying illness/pre-existing condition and dies and death certificate cannot be issued.
 - Child has an underlying illness/pre-existing condition but the death does not appear to be connected and death certificate cannot be issued.
- Occurs in custody, or where the child was detained under the Mental Health Act
- Where the initial circumstances raise any suspicions that the death may not have been natural
- In the case of a stillbirth where no healthcare professional was in attendance. Excludes all other stillbirths, miscarriage or termination carried out within the law.